

INDIAN SPINAL INJURIES CENTRE

THE POWER OF THE MIND

NEURO-UROLOGY MAGAZINE

THIRD EDITION

Visceral Rehabilitation

Safe Bladder and Sexuality health Talk for SCI

A portrait of Major H.P.S. Ahluwalia, an elderly man with a white beard and a white turban, wearing a dark blue suit and a dark blue tie. He is seated in a wheelchair, with his hands resting on his lap. A medal is visible on his left lapel. The background is a plain, light-colored wall.

Major H.P.S. Ahluwalia

ERADICATE "NEGLECTED NEUROGENIC BLADDER" BY 2030 CAMPAIGN

WORDS OF WISDOM

FROM MRS. BHOLI AHLUWALIA

THE CHAIRPERSON, INDIAN SPINAL INJURIES CENTRE, NEW DELHI

Dear Readers and our friends with Spinal Cord Injury across the country,

At the Indian Spinal Injuries Centre (ISIC), our unwavering dedication to serving the spinal cord injury (SCI) community across India and abroad is rooted in our vision and mission. We are proud to offer state-of-the-art spine surgery, orthopedics, and comprehensive rehabilitation services. Our commitment also extends to providing essential urological guidance, with a special focus on urinary and sexual health needs.

ISIC is a beacon of hope and healing for those people affected by spinal cord injuries. Our comprehensive approach ensures that every patient receives the highest standard of medical care, tailored to their unique needs. From advanced surgical interventions to holistic rehabilitation programs, we strive to enhance the quality of life for our patients.

Understanding the critical importance of urological and sexual health, our dedicated neurourology team provides specialized care to address these vital aspects. We believe that addressing urinary and sexual health is integral to overall well-being and recovery.



In addition to our in-person services, we have embraced distance care through online teleconsultation, ensuring that support is always within reach, no matter where you are. Our teleconsultation services allow us to extend our expertise and care to patients who may not be able to visit our center, providing them with the guidance and support they need.

At ISIC, we pledge our wholehearted support for your lifelong care, empowering you to lead a fulfilling and healthy life. Our commitment to you is unwavering, and we will continue to innovate and expand our services to meet the evolving needs of the SCI community.

MRS. BHOLI AHLUWALIA
CHAIRPERSON, INDIAN SPINAL INJURIES CENTRE



EXPLORING THE SCI REHABILITATION

Comprehensive Rehab is the source of Good Health and Long life

Spinal cord injuries (SCI) can be devastating, often leading to severe physical, emotional, and social challenges. These injuries can result from trauma, disease, or degeneration and frequently lead to partial or complete loss of motor and sensory functions below the level of injury. Despite these significant challenges, rehabilitation serves as the feather in the crown of recovery, enabling patients to regain independence, improve their quality of life, and reintegrate into society

The Scope of Rehabilitation

Rehabilitation for SCI patients is a multifaceted process that begins as soon as possible after the injury. It involves a comprehensive approach that includes physical therapy, occupational therapy, psychological support, and social integration programs. The primary goals are to maximize physical function, enhance psychological well-being, and foster social participation.



Physical Rehabilitation: Restoring Mobility and Independence

Physical therapy is at the core of rehabilitation for SCI patients, focussing on:

·**Restoring Strength and Mobility:** Tailored exercises help strengthen muscles, improve coordination, and enhance mobility. For those with partial motor function, physical therapy can significantly improve the ability to perform daily activities independently.

·**Preventing Secondary Complications:** Early and continuous physical activity helps prevent complications such as **pressure sores, deep vein thrombosis, and muscle atrophy**. These complications can severely hinder recovery and reduce the overall quality of life.

·**Adapting to New Realities:** When full recovery of mobility isn't possible, physical therapy aids in adapting to new ways of movement, often involving **assistive devices like wheelchairs, braces, or prosthetics**. This adaptation is crucial for maintaining an active lifestyle.

Occupational Therapy: Enhancing Daily Living

Occupational therapy complements physical rehabilitation by focusing on improving the ability to perform everyday tasks. This includes:

Skill Development: Teaching patients how to use adaptive techniques and tools to perform daily activities such as dressing, bathing, and cooking independently.

Home and Workplace Modifications: Recommending modifications to the home and workplace to make these environments more accessible and safer for individuals with SCI.

Vocational Training: Helping patients develop new skills or adapt existing ones to re-enter the workforce, which is essential for financial independence and psychological well-being.

Psychological Support: Nurturing Mental Health

·The psychological impact of SCI is profound. Patients often experience depression, anxiety, and a sense of loss. Psychological support is a critical component of rehabilitation, providing:

·**Counseling and Therapy:** Professional counseling helps patients cope with the emotional aftermath of their injury, fostering resilience and a positive outlook on recovery.

·**Peer Support Groups:** Connecting with others who have experienced similar injuries can provide invaluable support, encouragement, and practical advice, reducing feelings of isolation.

·**Family Education:** Educating family members and care givers about the challenges and needs of SCI patients ensures a supportive home environment, which is essential for recovery. Qualified and trained Nurses and peer counsellors can support the efforts of the psychologist in this essential initiative. A well adjusted patient has the best chance of successfully undertaking the rigour of Physiotherapy and to deal with challenges of th life ahead.

EXPLORING THE SCI REHABILITATION

Social Integration: Rebuilding Community Connections

Reintegration into society is a crucial aspect of rehabilitation. Social programs and community involvement play a significant role by:

Promoting Participation in Activities: Encouraging involvement in sports, hobbies, and social events helps rebuild confidence and social networks.

Advocating for Accessibility: Working with community organizations to improve accessibility in public spaces, transportation, and services ensures that individuals with SCI can participate fully in community life.

Empowering Independence: Providing resources and support for independent living enables patients to live fulfilling, autonomous lives.

Rehabilitation transcends mere physical healing; it is a tapestry woven from threads of renewal and restoration.

By embracing the holistic realms of physical, emotional, and social recovery, profound rehabilitation bestows upon those with spinal cord injuries the gift of a vibrant, purposeful existence.

Though the odyssey may be arduous, with the guiding light of unwavering support, individuals can sculpt new destinies, embodying the resilience and boundless fortitude of the human spirit.

Indeed, rehabilitation stands as a beacon of transformation, illuminating lives with the promise of renewal and the blossoming of hope.



Visceral Rehabilitation : a grossly neglected aspect of health in persons with SCI in india.

Dr. Dinesh Suman, Director Neurourology and SCI Andrology

Spinal cord injuries (SCI) bring about challenges that go beyond just moving around and physical activity. For a full recovery, it's important to also focus on visceral rehabilitation, which means taking care of bladder, bowel, and sexual health. These areas are crucial for helping patients live a healthy, socially active, and well-adjusted life.

Neurogenic Bladder Rehabilitation: Managing Urinary system Health

Bladder problems are common for SCI patients, put together as Neurogenic bladder, leading to issues like incontinence (loss of bladder control), urinary tract infections, and kidney damage. **Aim of management is to preserve kidney functions, prevent avoidable complications and minimize incontinence.**

Neurogenic Bladder rehabilitation can help in sustaining good health and longevity:

Bladder Training Programs: These programs teach you how to establish a regular schedule for urination, which can reduce accidents and improve bladder control.

Catheterization: Sometimes, using a catheter (a tube to help empty the bladder) is necessary. This can be done intermittently (every few hours) or with a long-term catheter, helping to prevent complications and make you more comfortable.

Medication: Medicines can help manage bladder spasms and improve control.

Surgical Options: In some severe cases, surgery might be needed to fix bladder issues.

Neurogenic Bowel Rehabilitation: Ensuring Gut Health

Bowel management is just as important, as SCI can cause constipation, incontinence, or irregular bowel movements. Bowel rehabilitation can help:

Diet and Hydration: Eating a high-fiber diet, use of laxatives and drinking plenty of fluids helps promote regular bowel movements.

Bowel Training Programs: Establishing a consistent schedule for bowel movements using techniques like commode training and use of suppositories.

Medication: Using laxatives, stool softeners, or other medicines to manage bowel function effectively.

Assistive Devices: Tools that help with bowel movements, ensuring safety and comfort. such as use of suppository, enema and Transanal irrigation

Visceral Rehabilitation : a grossly neglected aspect of health in persons with SCI

Sexual Rehabilitation: Enhancing Intimacy and Relationships:

Sexual health is vital for overall well-being and quality of life. SCI can affect sexual function, desire, and relationships. sexual rehabilitation helps by:

Education and Counseling: Providing information on how SCI affects sexual function and offering strategies to adapt sexual activity accordingly.

Therapeutic Interventions: Using medications, devices, or surgical options to enhance sexual function and satisfaction.

Psychological Support: Counseling to address the emotional and relational aspects of sexuality, helping patients and their partners navigate changes and maintain intimacy.

Peer Support and Resources: Connecting patients with support groups and resources that address sexuality and relationships post-injury.

Integrating Visceral Rehabilitation into Comprehensive Care: Visceral rehabilitation should be part of the overall care plan for SCI patients at every spine unit in India. This means every spine unit in the country must evolve to have :

- **Multidisciplinary Teams:** Working with specialists like urologists, gastroenterologists, psychologists, and sexual health experts to provide comprehensive care.
- **Personalized Rehabilitation Plans:** Tailoring rehab programs to meet your unique needs and goals, ensuring all aspects of your health and well-being are addressed.
- **Continuous Education and Life long Support:** Providing ongoing education and support to you and your family to help adapt to changes and manage your condition effectively.

Conclusion: Empowering Full Recovery: Taking care of bladder, bowel, and sexual health is a key part of recovering from SCI.

By focusing on these areas, rehabilitation programs help you live a healthier, more independent, and socially engaged life.

Ensuring that visceral rehabilitation is part of your overall care plan is essential for achieving a truly adapted and fulfilling life.

This holistic approach not only restores physical function but also enhances your overall well-being, helping you build resilience and maintain a positive outlook on life after injury.

UNDER THE MICROSCOPE

IS SEXUALITY A TABOO SUBJECT ANYMORE?

SCI BUZZ >

When and how to talk to your spinal cord injury patients about their hidden sexual concerns

Sexual health remains a sensitive topic, but it is no longer as taboo as it once was.

With increased awareness and progressive approaches in healthcare, discussing sexuality has become an integral part of comprehensive patient care, especially for those with spinal cord injuries (SCI). Addressing sexual concerns openly and empathetically is crucial for the overall well-being of these patients.

Recognizing the Importance of Sexual Health

Sexual health is a vital aspect of human life, influencing emotional, psychological, and social well-being. For SCI patients, sexual health concerns can be significant yet often hidden due to embarrassment, stigma, or fear of judgment. These concerns might include changes in sexual function, desire, intimacy, and relationships. Healthcare providers must create a safe and supportive environment where patients feel comfortable discussing these issues.

When and How to Talk About Sexual Health:

Early in the Rehabilitation Process: Introduce the topic of sexual health soon after the injury, once the patient is stable. This timing helps normalize the discussion and sets the expectation that sexual health is an important part of overall care.

During Routine Follow up visits:

Regular follow-ups provide opportunities to revisit sexual health, allowing patients to ask questions and address concerns that may arise as they adjust to life post-injury.

When Patients Exhibit Signs of Concern: Look for cues indicating that a patient may have unspoken sexual health concerns, such as changes in mood, reluctance to discuss relationships, or indirect questions about bodily functions.

How to Talk About Sexual Health: Breaking the Ice

Create a Comfortable Environment: Ensure privacy and a relaxed setting. Use open body language and maintain eye contact to foster trust and make the patient feel at ease.

Use Clear and Sensitive Language:

Avoid medical jargon and be straightforward yet sensitive. Phrases like "sexual health," "intimacy," and "relationship concerns" can help frame the discussion positively.

IS SEXUALITY A TABOO SUBJECT ANYMORE

Normalize the Conversation: Reinforce that sexual health is a normal and important part of recovery. Statements such as, "Many people with SCI have questions about sexual health," can help reduce stigma. **Be Non-Judgmental and Empathetic:** Show empathy and avoid making assumptions. Listen actively and validate the patient's feelings and concerns. Provide

Comprehensive Information: Offer information on how SCI can affect sexual function, and discuss potential solutions such as medications, devices, or therapeutic interventions.

Encourage Questions: Prompt patients to ask questions by saying, "Do you have any concerns or questions about how your injury might affect your sexual health?"

Addressing Specific Concerns

Changes in Sexual Function: Explain how SCI can affect sexual function, including changes in sensation, erectile function, lubrication, and orgasm. Discuss medical and therapeutic options to address these changes.

Intimacy and Relationships: Talk about the impact of SCI on relationships and intimacy. Encourage open communication with partners and suggest counseling if needed.

Fertility and Family Planning: Address concerns about fertility and reproductive health. Provide information on fertility treatments and options for having children.

Providing Resources and Support

Educational Materials: Provide brochures, websites, and other resources that offer reliable information about sexual health and SCI.

Referrals to Specialists: Connect patients with specialists such as urologists, gynecologists, and sex therapists who have experience working with SCI patients.

Support Groups: Encourage participation in support groups where patients can share experiences and gain support from others facing similar challenges.

Conclusion:

Sexual health is an essential aspect of life that deserves attention and care, especially for those with spinal cord injuries. By addressing sexual concerns openly and empathetically, healthcare providers can help SCI patients navigate these challenges and enhance their quality of life. Normalizing the conversation and providing comprehensive support empowers patients to embrace their sexuality confidently and maintain healthy, fulfilling relationships.

EDUCATION AND AWARENESS IS THE KEY TO GOOD HEALTH

Dr. Dinesh Suman, Director, Neurourology & SCI Andrology, ISIC

5 KEY POINTS ON WHAT SCI PATIENTS SHOULD AVOID DOING IN RESPECT OF REPEATED URINE TESTING FOR URINARY INFECTIONS:

1. *Avoid Over-Testing Without Symptoms*

- Do not perform repeated urine tests without any symptoms of a urinary tract infection (UTI), such as burning during urination, fever, or cloudy urine. Over-testing can lead to unnecessary anxiety and treatments.

2. *Do Not Self-Diagnose*

- Do not attempt to diagnose a UTI solely based on frequent urine testing. Always consult with a healthcare provider to interpret the results and determine the need for treatment.

3. *Avoid Antibiotic Overuse*

- Do not seek antibiotics based on positive urine cultures without symptoms of a UTI. Overuse of antibiotics can lead to antibiotic resistance and other health complications.

4. *Do Not Ignore Doctor's Advice*

- Do not disregard your healthcare provider's recommendations regarding the frequency of urine tests. Follow their guidance on when and how often to test for infections.

5. *Avoid Poor Sample Collection*

- Do not collect urine samples in a non-sterile manner or from unclean containers, as this can contaminate the sample and lead to inaccurate results. Always follow proper sample collection procedures.

Safe Catheterization with prevention and early management of urinary infection is the key to good health and survival in persons with SCI

5 key points about the types of catheters used to manage neurogenic lower urinary tract dysfunction (NLUTD):

1. Intermittent Catheters

- Description: Single-use catheters inserted several times a day to empty the bladder.
- Advantages: Lower risk of infection compared to indwelling catheters; greater independence and control over bladder management.
- Types: Available in various materials (e.g., PVC, silicone) and designs (e.g., straight tip, coude tip).

2. Indwelling Urethral Catheters (Foley Catheters)

- Description: Catheters that remain in the bladder for an extended period (days to weeks) with a balloon at the end to keep them in place.
- Advantages: Continuous drainage of urine; useful for patients who cannot perform self-catheterization.
- Disadvantages: Higher risk of urinary tract infections (UTIs), bladder spasms, and catheter blockages.

3. Suprapubic Catheters

- Description: Surgically placed through the abdominal wall into the bladder for long-term use.
- Advantages: Reduced risk of urethral damage and discomfort; easier for some patients to manage than urethral catheters.
- Disadvantages: Requires surgical placement and maintenance; potential for infection at the insertion site.

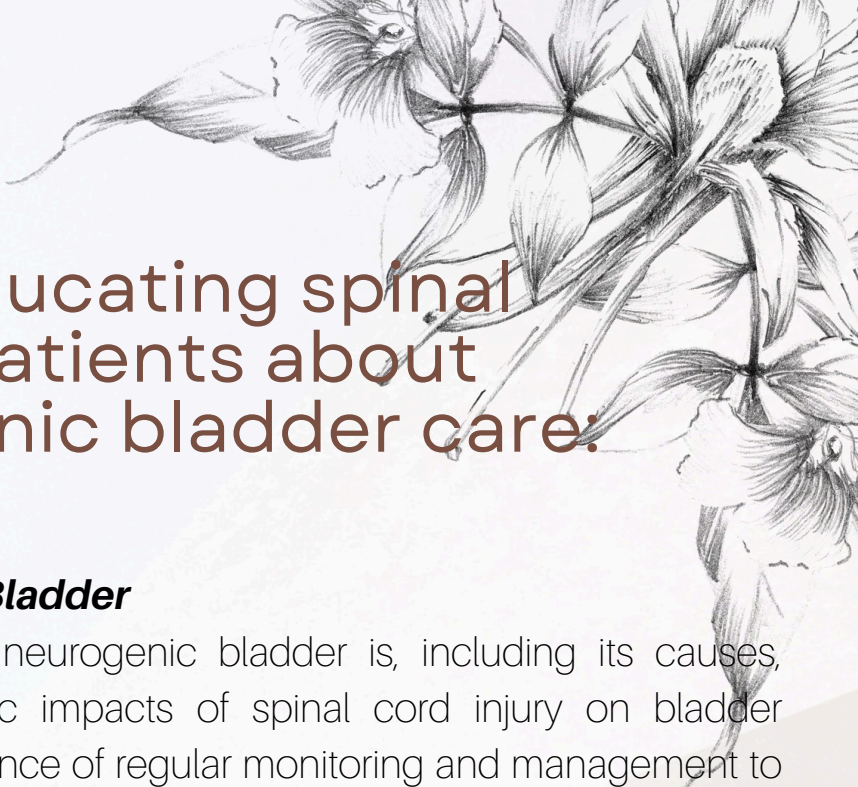
4. Condom Catheters (External Catheters)

- Description: External devices worn over the penis, connected to a drainage bag.
- Advantages: Non-invasive, comfortable for some male patients; reduces the risk of infection compared to indwelling catheters.
- Disadvantages: Not suitable for patients with significant urinary retention; potential for skin irritation and dislodgement.

5. Gibbon's Self-retaining Plain Catheters (with a tie/tape)

- Description: Catheters designed with a tie for retention.
- Advantages: Easier to insert in patients with an enlarged prostate or urethral stricture; may reduce trauma during catheterization. self insertion by patient possible.
- Disadvantages: Requires proper training for insertion to avoid complications; not suitable for all patients.

Safe Catheterization with prevention and early management of urinary infection is the key to good health and survival in persons with SCI



5 key points for educating spinal cord injury (SCI) patients about standard neurogenic bladder care:

- ***Understanding Neurogenic Bladder***

- Educate patients on what neurogenic bladder is, including its causes, symptoms, and the specific impacts of spinal cord injury on bladder function. Explain the importance of regular monitoring and management to prevent complications such as infections, kidney damage, and bladder stones.

- ***Clean Intermittent Catheterization (CIC)***

- Train patients on the proper technique for Clean Intermittent Catheterization, emphasizing hygiene to prevent infections.
- Provide clear instructions and demonstrations, and ensure they understand the frequency and timing for catheterization based on their individual needs.

- ***Medication Management***

- Inform patients about the medications used to manage neurogenic bladder, including anticholinergics and other drugs like low-dose tamsulosin.
- Explain how these medications work, their potential side effects, and the importance of adherence to prescribed regimens.

- ***Monitoring and Regular Check-ups***

- Stress the importance of regular follow-ups with their healthcare provider to monitor bladder function and detect any complications early.
- Encourage patients to keep a bladder diary and report any changes in symptoms or new issues promptly.

- ***Lifestyle and Support***

- Advise on lifestyle modifications that can support bladder health, such as fluid management, diet, and physical activity.
- Provide information on resources and support systems available, including patient education websites and youtube channels like SCIBLADDER.COM and elearnsoci.org etc.

Open the Doors to Good Health



5 key points on what SCI patients should NEVER DO with respect to long-term urological follow-up:

By Dr. Dinesh Suman

1. Never Miss your Appointments

- Do not skip or miss scheduled follow-up appointments with your urologist or healthcare provider.

Regular check-ups are essential for monitoring bladder function, identifying any emerging issues early, and adjusting treatment plans as needed.

2. Do Not Disregard Changes in Symptoms

- Do not ignore any changes in urinary symptoms, such as increased frequency, leakage, or discomfort.

These changes may indicate the need for adjustments in medication, catheterization routines, or other aspects of your urological care.

3. Never Self-Adjust Medications

Do not stop or alter medication dosages or frequency without consulting your Doctor. Changes should be made based on professional advice to ensure effective management of bladder function and minimize risks.

Serious harm may occur due to such negligent actions, so do discuss with your Doctor, even if contemplate any changes in your medication schedule.

4. Do Not Neglect Lifestyle Modifications

- Do not neglect lifestyle modifications recommended by your healthcare provider, such as dietary changes, fluid management, and exercises to support bladder health. These measures help optimize bladder function and overall well-being.

5. Never Delay in Reporting of Complications

- Do not delay reporting any complications, such as urinary tract infections, bladder stones, or catheter-related issues, to your healthcare provider. Prompt attention can prevent complications from worsening and improve outcomes.



5 key points on what SCI patients should AVOID doing in respect to fertility concerns after spinal cord injury (SCI):

1. ***Never Assume infertility just because you have SCI*** - Do not assume you are

infertile without consulting a fertility specialist or urologist. Most men with SCI may still have viable sperm and potential fertility. Testing is necessary to assess fertility status accurately.

2. ***Do Not Delay Seeking Urologist's Advice:*** Do not delay seeking advice from

a fertility specialist or urologist experienced in SCI-related fertility issues. Early consultation allows for timely evaluation and discussion of fertility preservation options.

3. ***Never Discontinue Birth Control Without Doctor's guidance:***

- Do not discontinue birth control methods assuming infertility after SCI. Sperm can sometimes still be viable, and pregnancy remains a possibility. Discuss contraceptive options with your doctor to avoid unintended pregnancies.

4. ***Do Not Ignore Emotional Impact:***

- Do not ignore the emotional impact of fertility concerns after SCI. It is normal to feel distressed or anxious. Seek support from counselors, support groups, or mental health professionals to address emotional well-being.

5. ***Avoid Unproven Fertility Treatments:*** Do not pursue unproven

fertility treatments or interventions without consulting healthcare providers. Some treatments may not be suitable or effective for SCI-related fertility issues. Stick to evidence-based approaches recommended by specialists.

Navigating fertility concerns after SCI requires careful consideration, consultation with specialists, and support to address both physical and emotional aspects of fertility preservation and family planning.